

Engaging Patients in Trials: From Science to Practice



Canada Research Chair
in Patient and Public
Partnership

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Centre of Excellence on Partnership
with Patients and the Public

Engaging with Patients in Trials

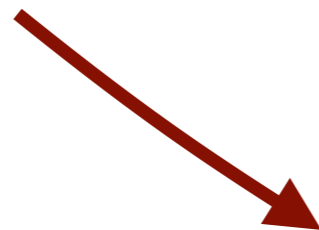
The Science

The Practice

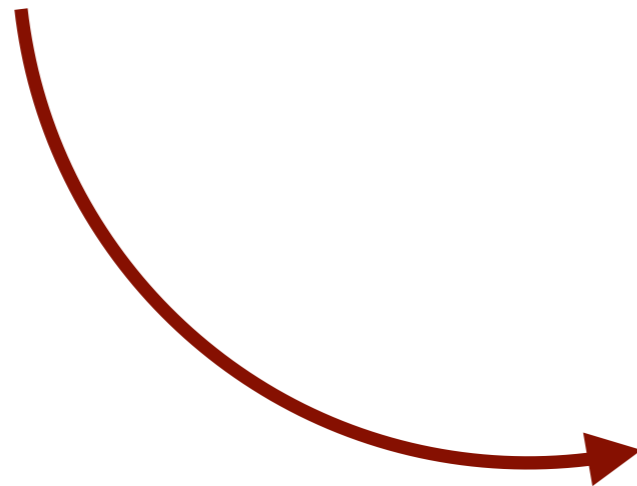
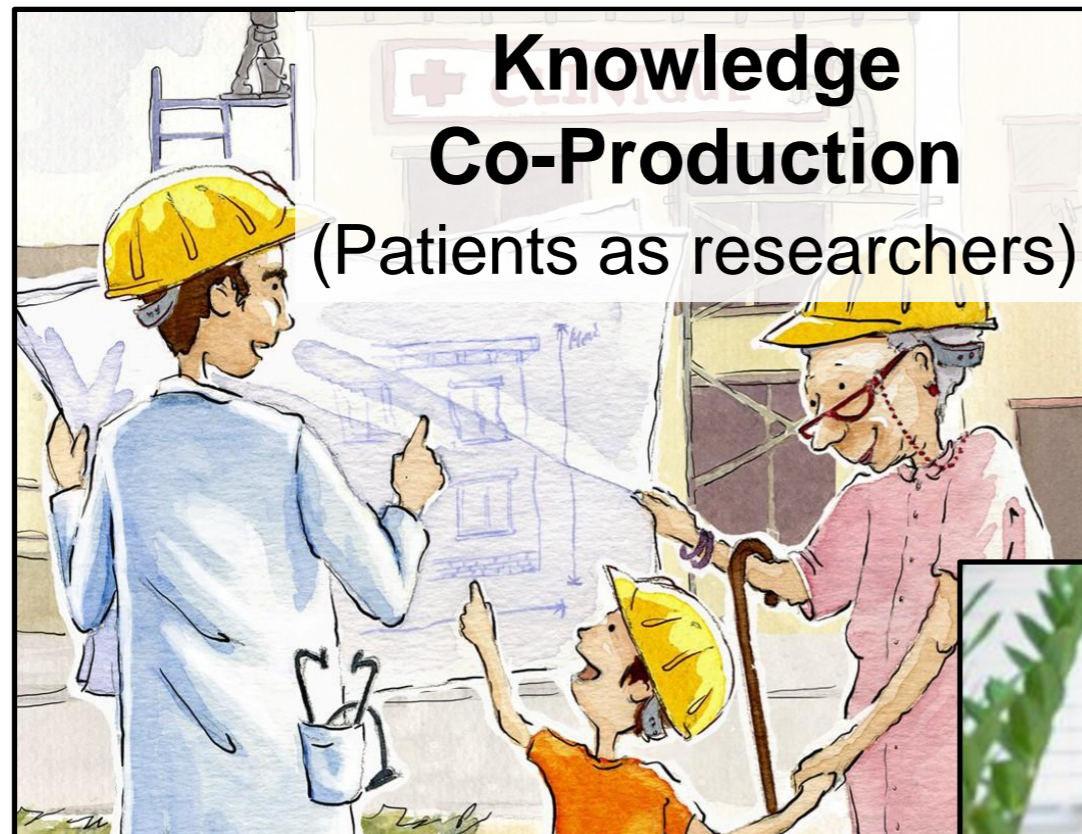
Engaging with Patients in Trials

The Science

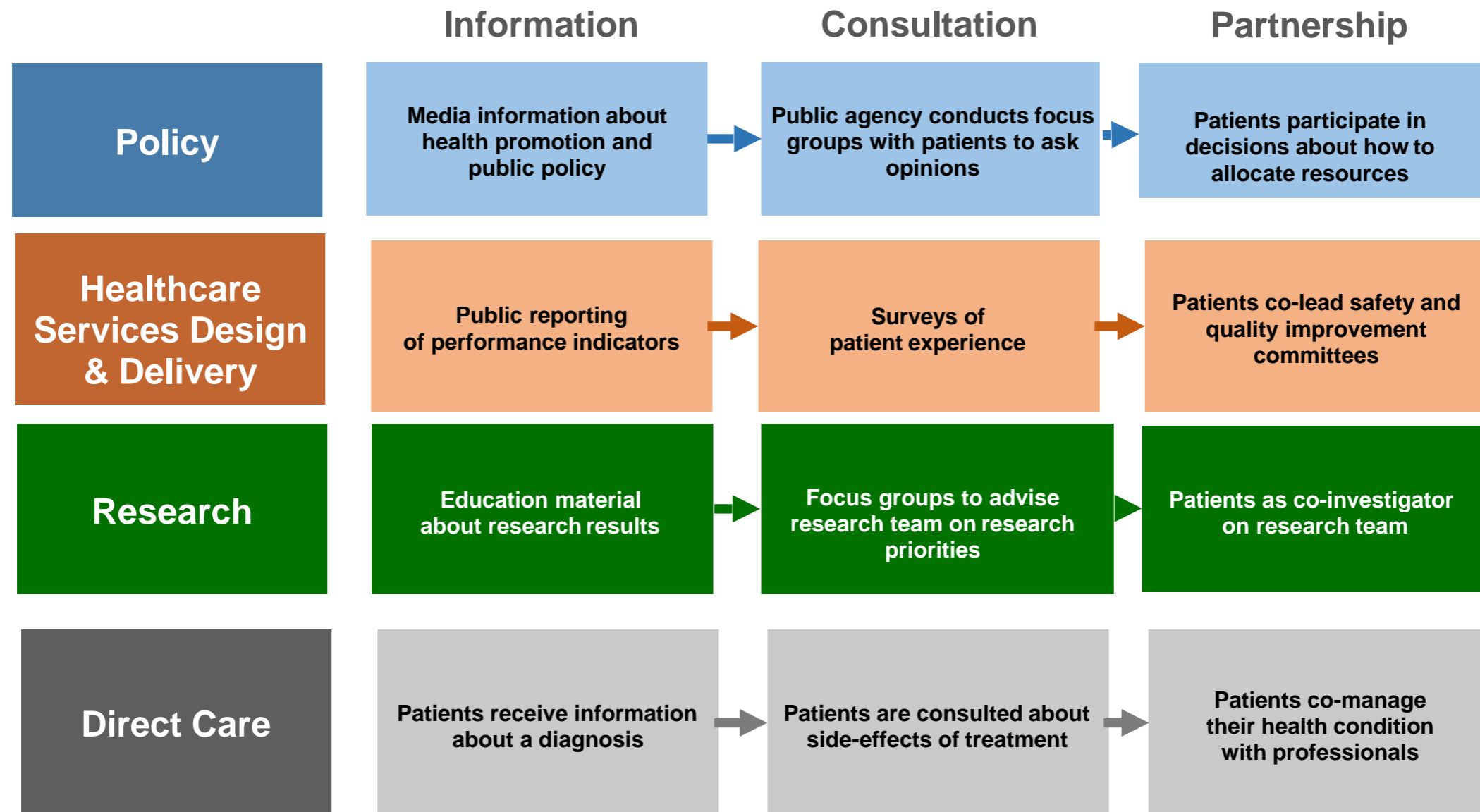
From research subjects



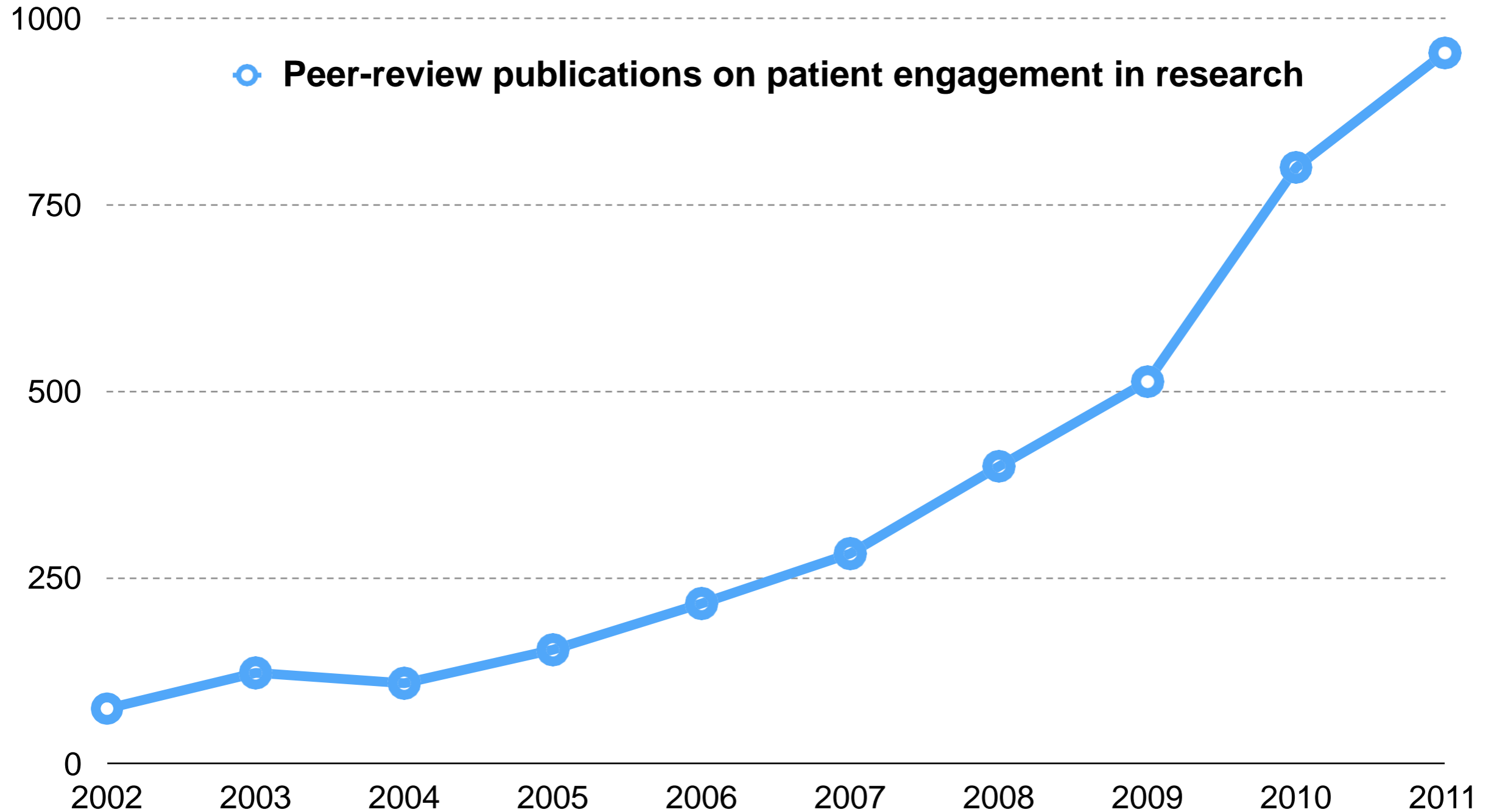
To research partners



Engagement in what?



An Emerging Science



The research community **remains divided**

ADVOCATES

**More Relevant
Research**

**Better Use in
Practice**

**Improved
Patient-Oriented
Outcomes**

AGNOSTICS

**WHERE IS
THE
EVIDENCE?**

ATHEISTS

**Biased
Research**

**Patients not
representatives**

**Conflicts of
Interests**

Engagement at what stage?

UPSTREAM
Doing the right research...

Priority-setting
Question
Governance

DOWNSTREAM
The research right...

Recruitment
Implementation
Knowledge translation

Potential benefits

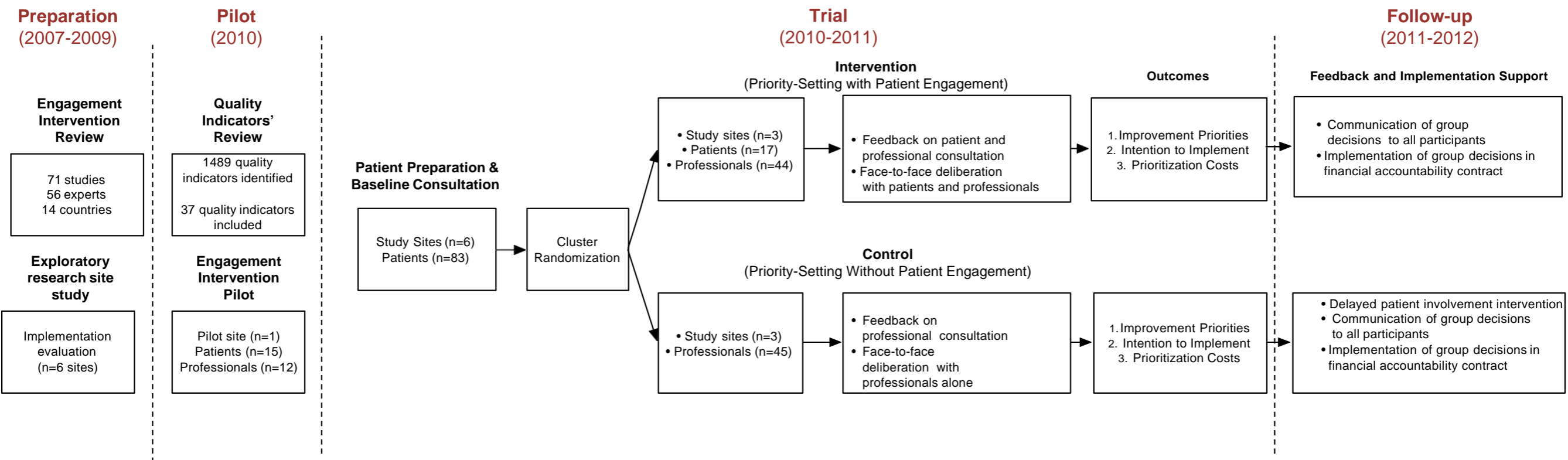
of patient engagement in research

- **Doing the right research...**
 - **Alignment of research priorities** with patients' needs
 - Include **relevant outcome** (eg. fatigue, sleep, social isolation)
- **Doing the research right...**
 - Increased **recruitment rates**
 - More **logistically & culturally appropriate research**
 - Increased **sustainability of projects** beyond research project funding

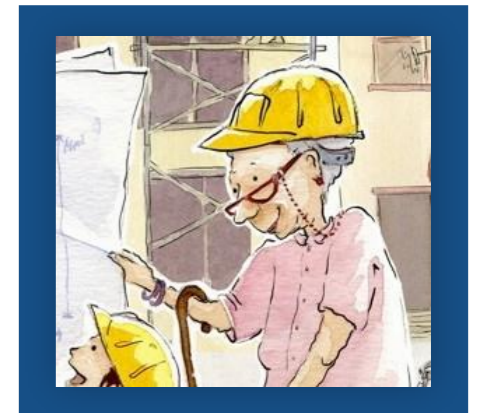
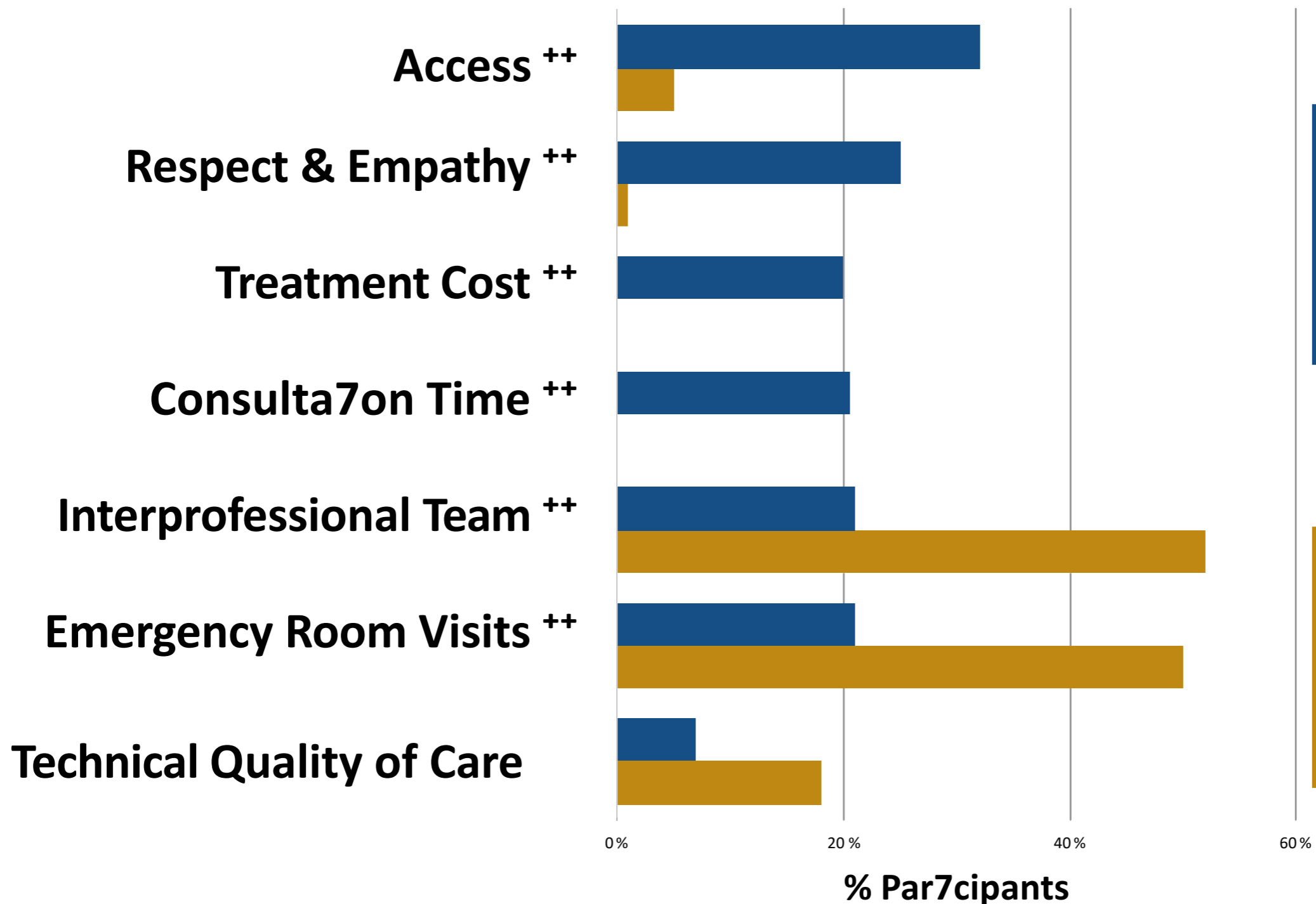
Patient engagement in priority-setting

A cluster randomized trial

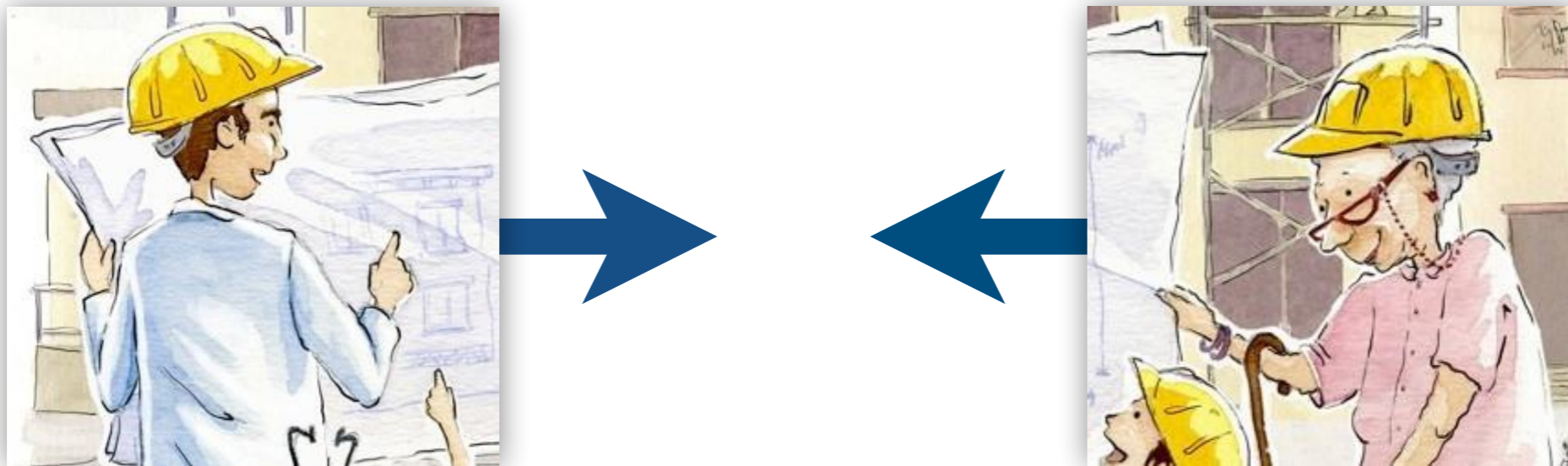
(2007-2012)



Patients and professionals have different priorities



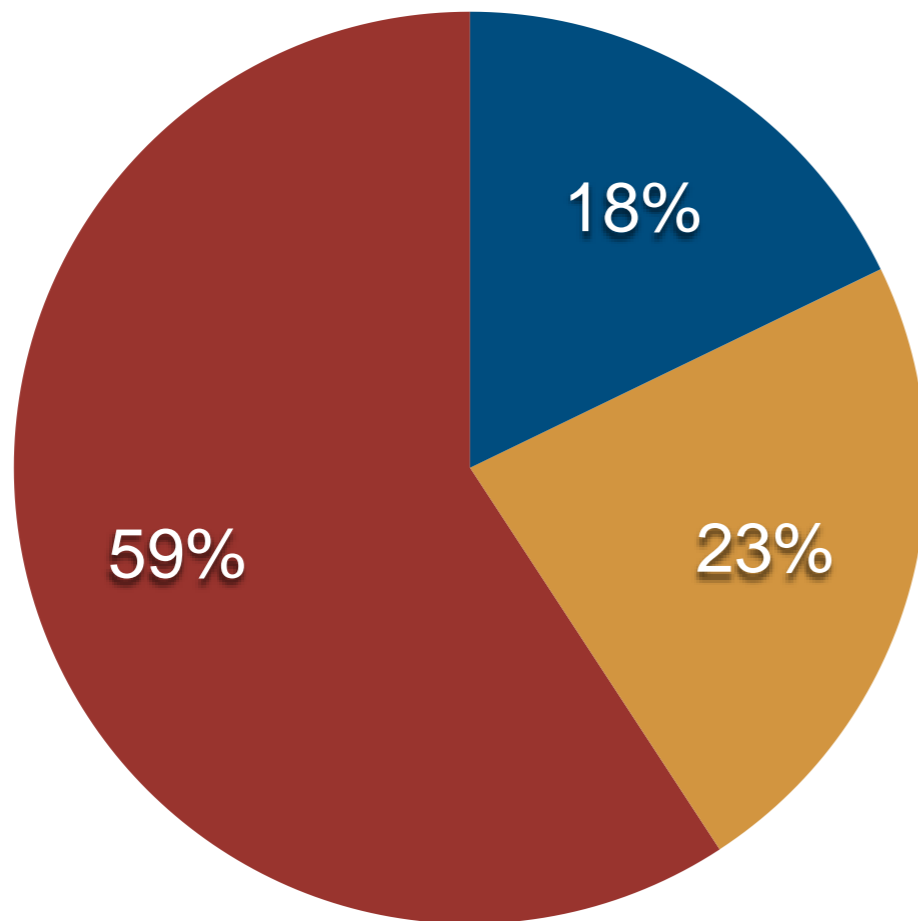
Patients and professionals can agree on common priorities



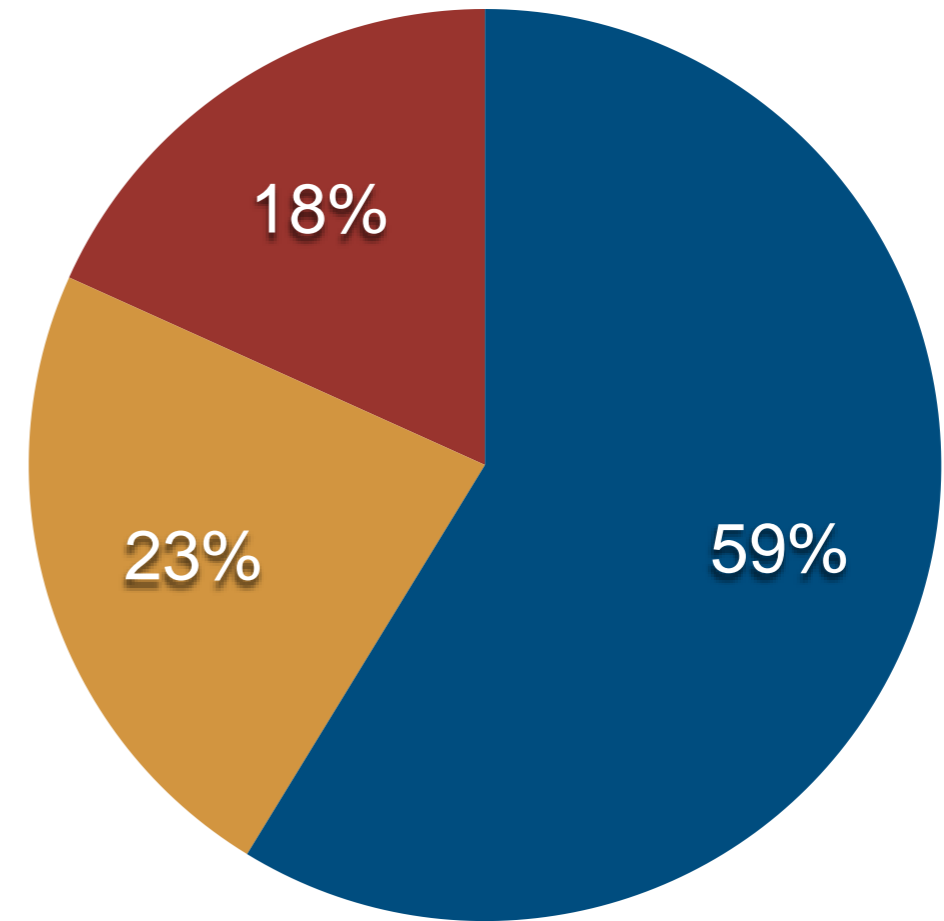
Mutual Agreement ↑ 42% absolute increase
($p < 0,01$)

Patient Engagement Changes Priorities for Research

**Registered
Randomized Trials**



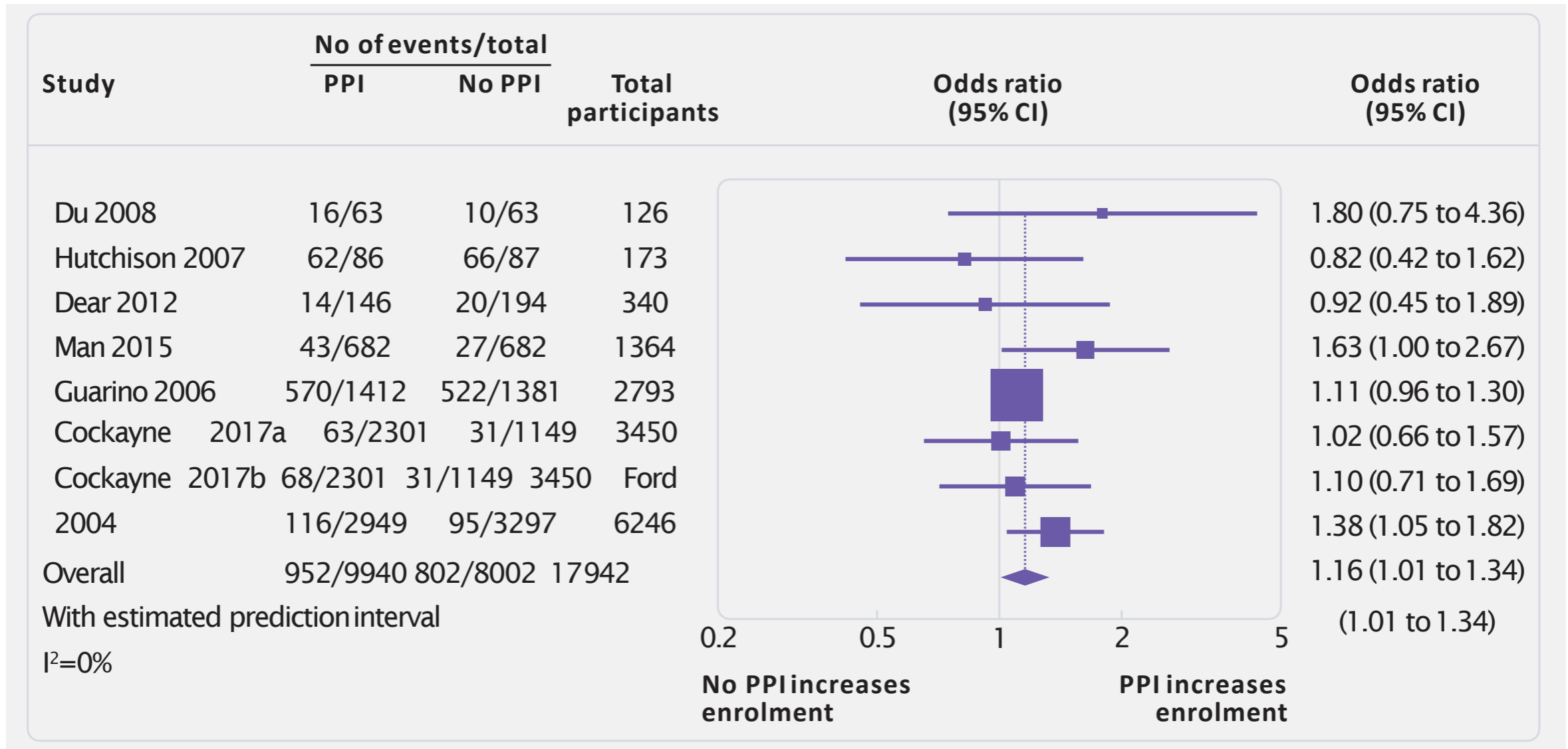
**Patient-clinicians
research priorities (JLA)**



- **Psychosocial interventions, Education, Healthcare delivery**
- **Medical technologies**
- **Medications**

Patient Engagement increases recruitment in clinical trials

Effects of patient and public involvement (PPI) on enrolment in clinical trials
Meta-analysis of randomized studies

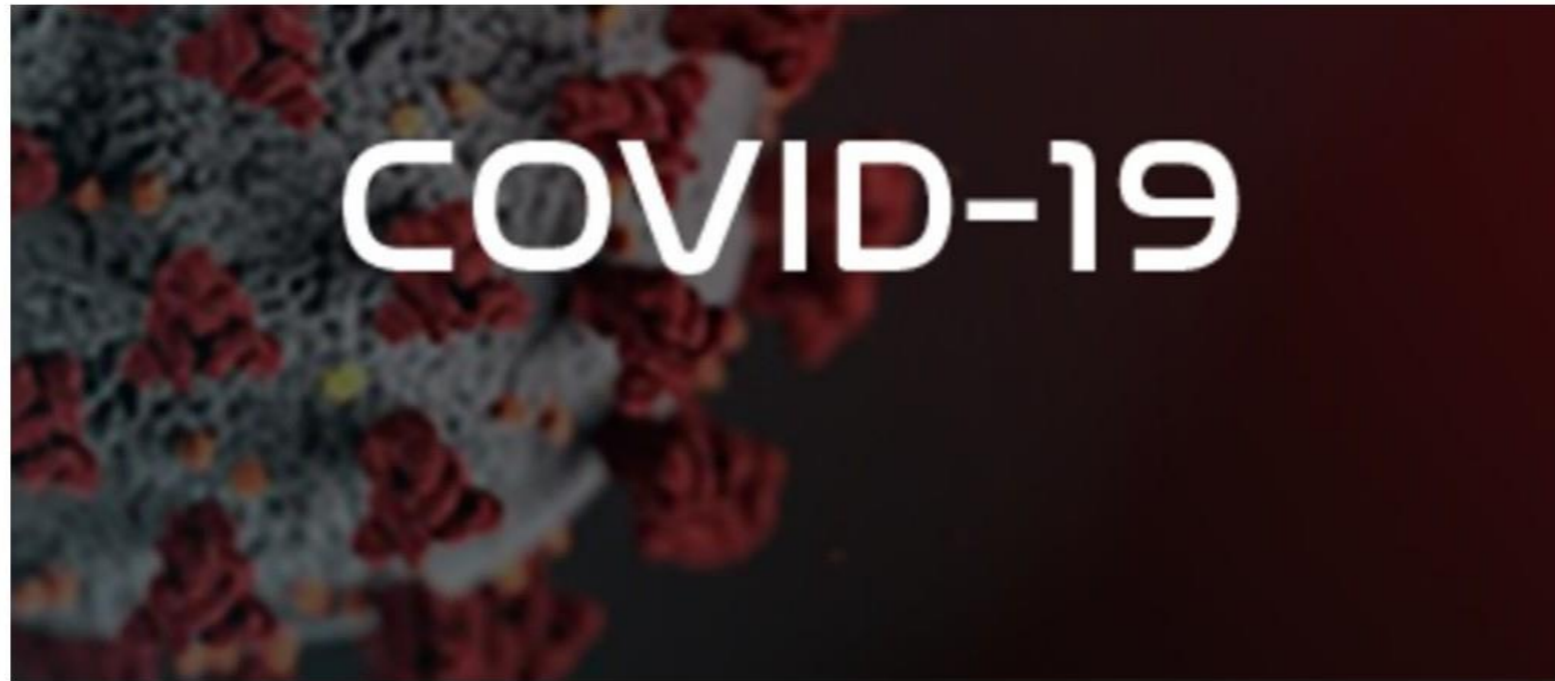


Involvement of patients with lived experience of the condition significantly associated with improved recruitment (p=0.02)

Engaging with Patients in Trials

The Practice

Engaging with patients from the beginning



Impact of the COVID-19 pandemic on immunosuppressed graft/tissue/stem cell recipients and their relatives

We are still recruiting transplant recipients and their family members interested in contributing, as a volunteer research participant, to a study aimed at understanding the *Impact of the COVID-19 pandemic on immunosuppressed graft recipients and their relatives*.

More specifically, this project aims to capture the modification of lifestyle habits, stress, anxiety levels and coping strategies of immunosuppressed graft recipients, their families and their relatives in the specific context of the containment associated with COVID-19 (objective 1). We also wish to study the impact of pet ownership on the stress experienced by this population and the benefits that pets can bring to organ recipients and their families (objective 2).

Please contact Stéphanie (stephanie.lariviere-beaudoin.chum@ssss.gouv.qc.ca), the Project Manager, if you wish to learn more and join the study.

The research team.

Mélanie Dieudé (Ph.D.), **Isabelle Doré** (Ph.D.), **Sylvain Bédard** (Patient), Co-Investigators
and **Stéphanie Larivière**, Project manager

Are you ready to partner with patients?

1. **Willing to learn** from patients
2. Professional goals and **interpersonnel skills** compatible with partnership research (e.g. team player)
3. Ready to devote **time, energy and resources** to develop and maintain collaboration
4. **Flexible in research goals** and potential that current project will be rejected/changed by patients
5. Willing to **share power and leadership**

How do I start?

1. Clarify **goals and roles**
2. **How ready** are you?
3. **Start simple...**

Engaging with Patients in Trials

Key Messages

Engaging with Patients in Trials

1. **Engaging upstream** with patients **can help doing the right research** (questions, priorities and outcomes), and set the stage for doing research right (recruitment, implementation, adoption) when engaging downstream
2. Productive partnerships require the right **attitudes** (team players, willingness to learn from each other), **conditions** (time & resources) and **players** (relevant lived experience)
3. **Engagement is an art and a science**: start simple and learn together as you go

Thank you!

Together, I am Better

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